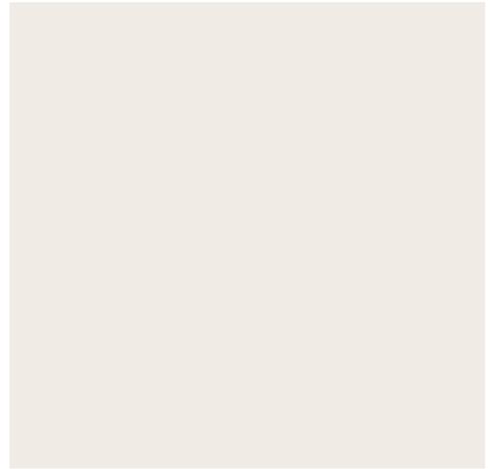


2021-22

DATA AT A GLANCE: FAMILY SURVEYS

Selected Findings from National Core Indicators® Intellectual and Developmental Disabilities
Adult Family Survey, Family Guardian Survey, and Child Family Survey



FAMILY SURVEYS: OVERVIEW

INTRODUCTION

The 2021-22 Data at a Glance: Family Surveys shows selected findings from National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) suite of family surveys: the Adult Family Survey (AFS), Family Guardian Survey (FGS), and Child Family Survey (CFS).

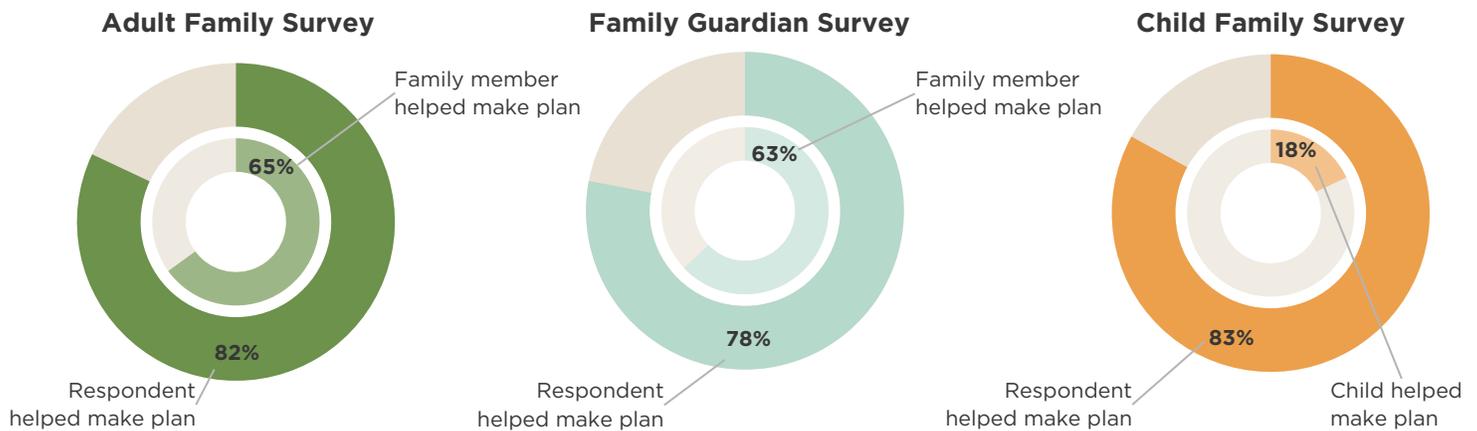
While reviewing this resource it is important to note the following:

- "Family member" refers to children or adults with intellectual or developmental disabilities who use long-term services and supports.
- "Respondent" refers to family members or guardians of the person using services.
- Data displayed in this resource reflect a selection of key outcomes. Please refer to the [AFS](#), [CFS](#), and [FGS](#) reports to learn about other important outcomes.

If you would like to learn more about NCI-IDD, visit: <https://idd.nationalcoreindicators.org/>

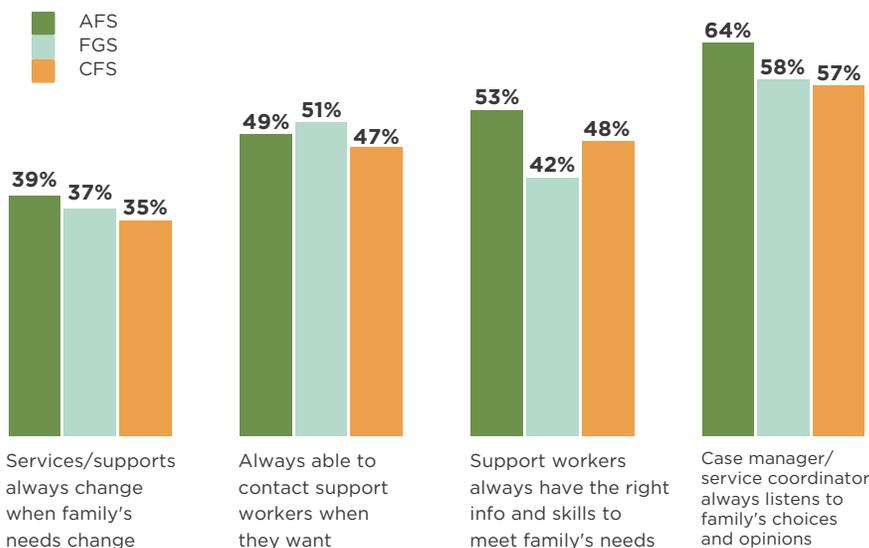
Questions? Email NCI Co-Director Dorothy Hiersteiner at: dhiersteiner@hsri.org

CROSS FAMILY SURVEY COMPARISONS



Person-centered planning requires that people who use services make the decisions about how their service plan is developed and what it includes. The above charts show that one-third of adult family members—the people who are using services—did not help make their service plan; among those who are under age 18, more than 80% did not help make their service plan. In contrast, a majority of the respondents (between 78% and 83%) indicated they helped make their family member’s service plan. This data shows that there is room to improve how service systems support the development of truly person-centered plans.

Family experience with services



This graph (left) shows responses to four questions about family experience with services. Across all surveys, less than 40% of respondents report that services change when their family's needs change. About half of respondents report that they can always contact support workers when they want and say workers always have the right information and skills to meet family's needs. Finally, more than one-third of respondents say that case managers do not always listen to their family's choices and opinions.

High rates of vacancies in the workforce may be contributing to the perception of poorer quality care. These data suggest that state systems need to focus not only on addressing workforce shortages, but also monitoring how shortages impact the outcomes of people who use services.

ADULT FAMILY SURVEY: SAMPLE DETAILS

SAMPLE SIZE

11,989 total respondents

GENDER AND AGE



59% Male
41% Female
0% Other, don't know, or unclear

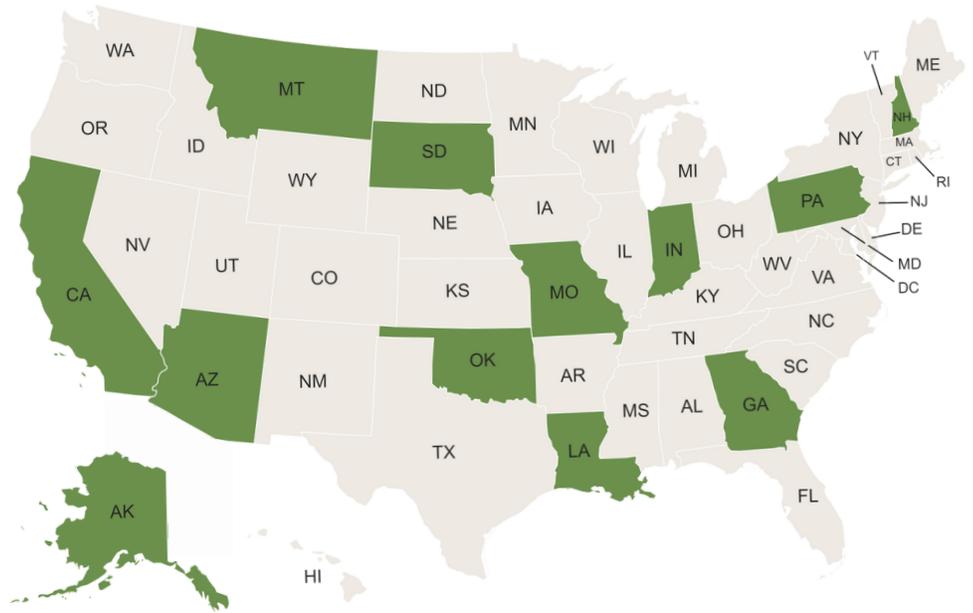
34.6 years old (average)

LOCATION

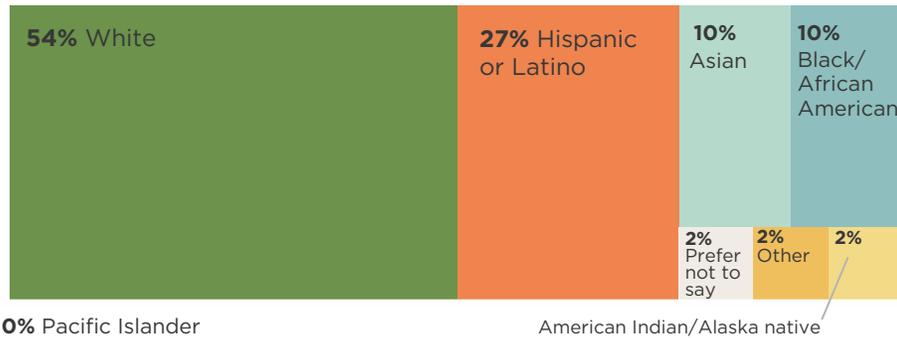
22% live in rural area
78% live in urban or suburban area



STATES INCLUDED



RACE AND ETHNICITY



DIAGNOSIS

Note: Diagnoses are not mutually exclusive.

66% Intellectual disability

38% Autism spectrum disorder

26% Seizure or other neurological disorder

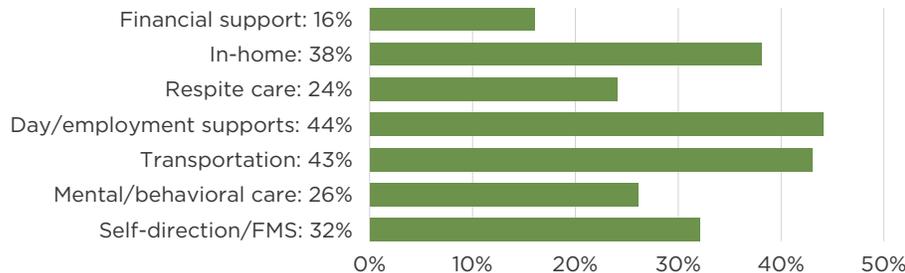
24% Mood or other psychiatric diagnoses

17% Cerebral palsy

15% Down syndrome

9% Limited/ no vision

SERVICES RECEIVED FROM DD AGENCY



PAID SUPPORTS



51% said respondent or other family member provides paid supports

GUARDIANSHIP



ADULT FAMILY SURVEY: OUTCOMES

FAMILY SATISFACTION

44% said they are ALWAYS satisfied overall with the services and supports their family member currently receives

- The highest state rate was **55%**
- The lowest state rate was **34%**



INFORMATION AND PLANNING

Case manager/service coordinator **always** listen to family's choices and opinions

64%

Plan includes **all** the services and supports family member needs

86%

ACCESS AND DELIVERY

Family member gets **all** the services listed in the plan

83%

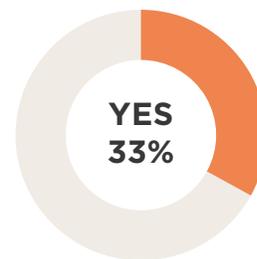
Family gets the supports and services it needs

73%

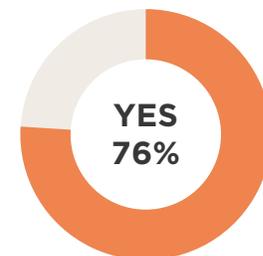
Services are **always** delivered in a way that is respectful of family's culture

80%

WORKFORCE

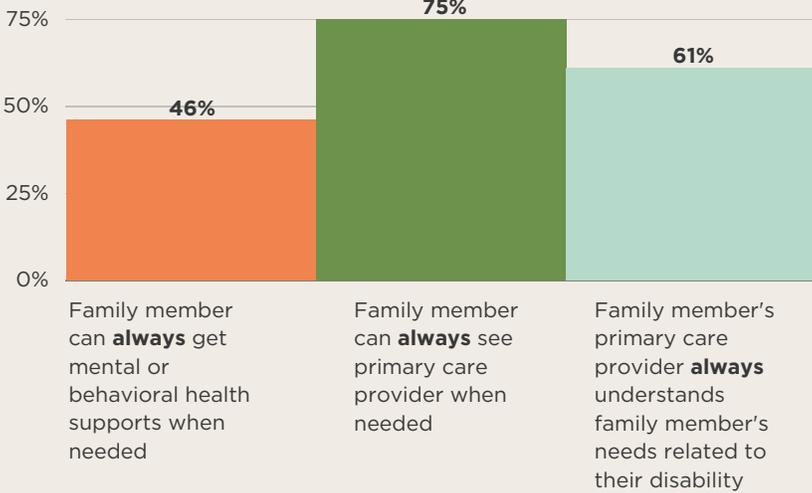


Family member's support workers change too often; there is too much "turnover" of support workers



There is **always** a staff person available to support family member when support is needed

HEALTH AND SAFETY



COMMUNITY CONNECTIONS

Family member does things in the community

80%

Family member has friends other than paid support workers or family

58%

CHOICE AND CONTROL

27% said YES, they, their family member, or someone else in the family chose their family member's case manager/service coordinator



59% said someone in the family can ALWAYS change their family member's support workers

CHILD FAMILY SURVEY: OUTCOMES

FAMILY SATISFACTION

36% said they are ALWAYS satisfied overall with the services and supports their child currently receives

- The highest state rate was **52%**
- The lowest state rate was **28%**



INFORMATION AND PLANNING

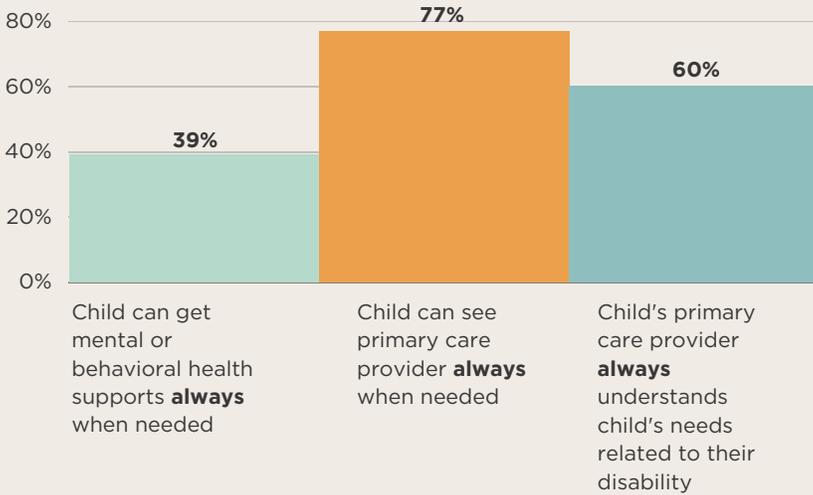
Case manager/service coordinator **always** listen to family's choices and opinions

57%

Plan includes **all** the services and supports family member needs

81%

HEALTH AND SAFETY



ACCESS AND DELIVERY

Child gets **all** the services listed in the plan

81%

Family gets the supports and services it needs

64%

Services are **always** delivered in a way that is respectful of family's culture

80%

COMMUNITY CONNECTIONS

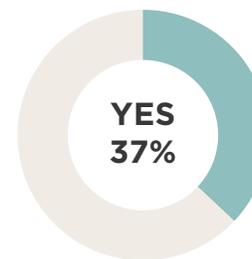
Child does things in the community

71%

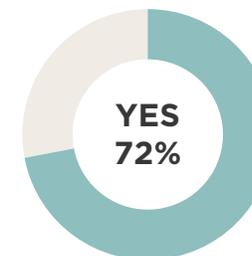
Child spends time with children who do not have DD

83%

WORKFORCE



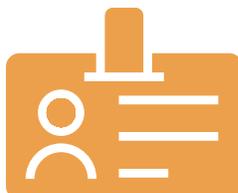
Do your child's support workers change too often? Is there too much "turnover" of support workers?



Is there always a staff person available to support your child when support is needed?

CHOICE AND CONTROL

19% said YES, they or someone else in the family chose their child's case manager/service coordinator



52% said someone in the family can ALWAYS change their child's support workers

FAMILY GUARDIAN SURVEY: OUTCOMES

FAMILY SATISFACTION

44% said they are ALWAYS satisfied overall with the services and supports their family member currently receives

- The highest state rate was **51%**
- The lowest state rate was **23%**



INFORMATION AND PLANNING

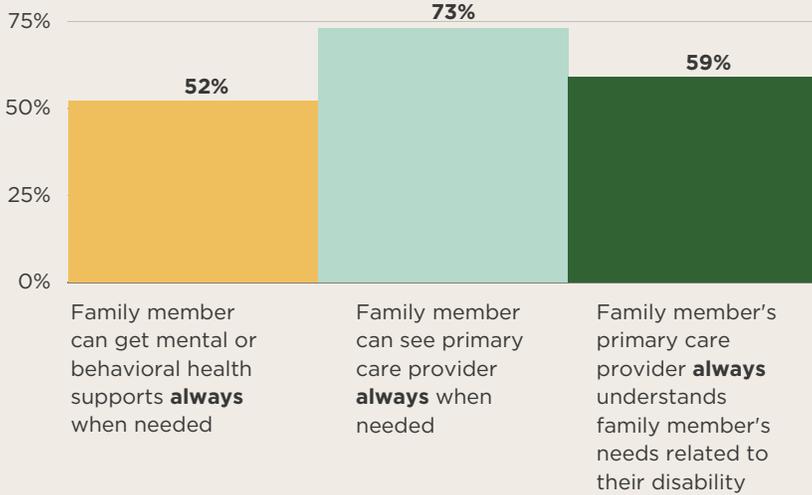
Case manager/service coordinator **always** listen to family's choices and opinions

58%

Plan includes **all** the services and supports family member needs

90%

HEALTH AND SAFETY



ACCESS AND DELIVERY

Family member gets **all** the services listed in the plan

88%

Family gets the supports and services it needs

86%

Services are **always** delivered in a way that is respectful of family's culture

77%

COMMUNITY CONNECTIONS

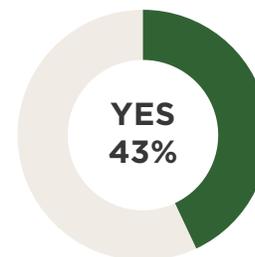
Family member does things in the community

83%

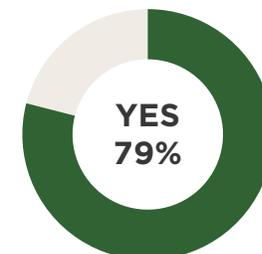
Family member has friends other than paid support workers or family

61%

WORKFORCE



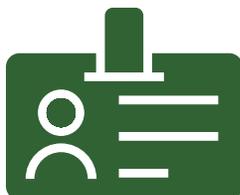
Do your family member's support workers change too often? Is there too much "turnover" of support workers?



Is there always a staff person available to support your family member when support is needed?

CHOICE AND CONTROL

16% said YES, they, their family member, or someone else in the family chose their family member's case manager/service coordinator



32% said someone in the family can ALWAYS change their family member's support workers